

Sexual & Gender Minority Health Research **LISTENING SESSION**



October 22, 2019
Summary Document



National Institutes of Health
Sexual & Gender Minority Research Office



SGM Health Research LISTENING SESSION

October 22, 2019 • Wilson Hall, Building 1 • 11 a.m. - 12 p.m.

SUMMARY DOCUMENT

Introduction

The National Institutes of Health (NIH) Sexual & Gender Minority Research Office (SGMRO) held a listening session with several sexual and gender minority (SGM)-focused health and health advocacy organizations. The primary objectives of the listening session were to: (1) gather comments, concerns, and suggestions about SGM-related health research and related activities at the NIH from community stakeholders; and (2) use this insight and feedback to help inform the development of the NIH FY 2021-2025 SGM health research strategic plan.

This is a summary of the session's discussion and does not represent official positions of the NIH or any other government agency.

Participants and Structure of Listening Session

The SGMRO hosted the listening session on October 22, 2019, at the Bethesda, MD, campus of the NIH. Twelve representatives from SGM health research and health advocacy groups (see **Appendix 1** for the list of participants) attended in person at the listening session. Invitees were selected based on the population, topic, and area of research covered by the organization to ensure that a diversity of perspectives was represented; several invitees were unable to participate. Any future listening sessions sponsored by the SGMRO will aim to take into account perspectives not represented at previous listening sessions. Attendees shared their perspectives on research priority areas with NIH leadership and staff from NIH Institutes, Centers, and Offices. The listening session provided a unique opportunity for leaders in SGM health and advocacy to voice concerns and bring attention to challenges in and barriers to SGM health research. The discussion was structured so that each participant was allotted 3-5 minutes to speak. The session was open to the public via phone-in, and an audio recording and transcript are available on the [SGMRO website](#). Public comment was accepted after the conclusion of the listening session; a summary of written comments is provided below.

Major Themes From Listening Session

After listening to participant commentary and reviewing the transcript, numerous themes and topics for consideration emerged from the session. These themes have been consolidated and are listed below:

- **Fund SGM Health Research**
 - Continue to invest in SGM health research across the agency.
 - Fund projects in areas such as basic science, measurement and methodological research, diversity of disease states, and health conditions.
 - Include SGM populations in research proposals submitted to the NIH.
 - Increase the proportion of funds to training grants and to Early Stage Investigators to foster a pipeline of researchers.

- **SGM Data Collection**

- Collect more data, particularly longitudinal data, to fill gaps in our understanding of SGM health outcomes.
- Require the inclusion of sexual orientation and gender identity (SOGI) questions and SGM-relevant questions in research proposals submitted to the NIH.
- Design health survey response categories to capture a fuller and broader range of SGM identities.
- Create data governance standards for how SGM data are collected, including a common understanding of the appropriate terminologies and categorizations and a universally agreed-upon method to organize and layer data.
- Address barriers that investigators, especially Early Stage Investigators, face when collecting preliminary SOGI data for grant applications.
- Capture SGM mortality/fatality data and train medical examiners and death investigators on best practices in capturing this data.
- Collect data to address the unique issues and health needs of queer and trans Muslim American youth.
- Support a network of community health centers and research hospitals to track ongoing clinical cohorts of SGM patients.

- **Scientific Research Gap Areas in SGM Health**

- **Intersectionality**

- Collect data on intersecting identities, which include (but are not limited to) race, ethnicity, ability, age, immigrant status, and religion.
- Utilize mixed-methods studies to gain insights on the outcomes of small groups.

- **Intervention Research**

- Investigate the efficacy of existing policies and interventions such as anti-discrimination policies (specifically in health care, prisons, and school systems) and medical and surgical interventions in transgender and intersex individuals.
- Create standardized metrics that can assess the efficacy of interventions on SGM populations.
- Develop the structural capacity to adequately capture larger quantities of data.
- Disseminate information to stakeholders in SGM health about interventions that already have proven to be efficacious.
- Make successful intervention protocols readily accessible to the groups and individuals best positioned to deploy them.
- Create group- and community-level interventions to promote a sense of community and reduce social isolation with SGM older adults, such as congregate meal programs, SGM elder bereavement groups, and SGM-friendly congregate housing.
- Investigate the experiences of prisoners and youth in the justice systems.
- Increase understanding of how comprehensive anti-bullying and harassment policies, support, and resources benefit SGM students and allies in the K-12 educational environment.
- Capture data on the inclusive SGM suicide prevention policies used by schools that have demonstrated a decrease in mental health disparities.

- **Transgender-Specific Health Research**

- Support additional research in areas of health care services, hormone therapy, violence, elders/aging, and ways to increase the life span of Black transwomen.

- **Conversion Therapy**
 - Support research on the harms attributed to conversion therapy, the impact of family acceptance and rejection, and interventions that foster acceptance among families.
- **Effects of Discrimination on Health**
 - Investigate how maltreatment in health care impacts health outcomes.
 - Investigate how discrimination broadly impacts overall health in the SGM community.
 - Provide safeguards to researchers who are targeted or harassed for conducting SGM health research.
 - Investigate and challenge assumptions about what SGM people are supposed to look like and what their health experience is supposed to be.
- **Bisexual-Specific Health Research**
 - Support additional research on the health of bisexual individuals as they are the single largest group within the SGM community.
- **Aging in SGM Populations**
 - Investigate the health needs of older adults who have experienced a lifetime of discrimination, stigma, and isolation and who are more likely to acquire disabling chronic conditions such as heart disease, diabetes, gynecological cancers, HIV/AIDS, and depression.
 - Develop a longitudinal long-term youth outcomes study.
 - Study experiences of SGM elders and older adults living with HIV in senior service settings to inform interventions.
- **SGM Youth**
 - Promote research on parent-child conversations about sexual health and healthy dating, HIV/Sexually Transmitted Infections and pregnancy prevention, and SGM identity and related issues.
 - Provide research opportunities to better understand the relationship between SGM youth's school experiences (e.g., feeling unsafe because of their sexual orientation or gender identity/expression, experiences of anti-SGM victimization) and health outcomes.
 - Support research that examines sex education policies in rural and socially conservative districts and its impact on health outcomes.
- **Intersex/Differences in Sex Development-Specific Health Concerns**
 - Investigate the consequences of stigma, minority stress, and variations of sex development on health outcomes.
 - Study and evaluate affirming practices and care in children with diverse sex traits.
 - Develop community-based participatory research to determine patient-centered outcome measures.
 - Collaborate with the International Rare Diseases Research Consortium to use their mixed-methods research protocols in studying the intersection of SGM status and rare conditions.
- **Social Determinants of Health**
 - Collect data that examine the intersection of health outcomes, social stigmas related to one's sexual orientation and/or gender identity/expression, and structural racism and White supremacy.

- Connect health outcomes with economic security and/or housing stability to develop a more holistic picture of SGM populations and how multiple attributes impact health.
 - **Health Disparities**
 - Assess health across the life span of SGM populations, with special care to include persons of color and individuals who identify as transgender and bisexual.
 - Focus on the study of chronic diseases that are more prevalent among Black and Latina women.
 - Investigate health outcomes related to coming out, which includes (but is not limited to) victimization, family rejection, depression, suicide, unemployment, unstable housing, and HIV risk.
 - Develop prevention and cessation interventions for vaping and E-cigarettes.
- **The Sexual & Gender Minority Research Office (SGMRO)**
 - Help advocates identify current NIH-funded SGM health research.
 - Collaborate with the *All of Us* Research Program to develop safeguards for the ethical use of SOGI data to combat the misuse of science to harm SGM populations.

Contributions From the Public Post-Listening Session

Following the listening session, the public was offered an opportunity to provide comments, questions, and/or feedback with the SGMRO via email. Five individuals/organizations shared feedback and the following are the main topics identified:

- **SGM Data Collection**
 - Include SGM populations located in rural, exurban-rural, small town rural, no-town rural, and remote areas in data collection efforts.
 - Ensure that research on SGM health-specific interventions and innovations is readily available and accessible to rural SGM populations.
 - Include individuals who desist transition and no longer seek medical services (sometimes referred to as “desisters”) in data collection as they become invisible to care providers and researchers when desistance occurs.
- **Scientific Research Gap Areas**
 - **Detransition/Desistance**
 - Investigate the health consequences of early social and medical transition on SGM youth.
 - Support research on health outcomes related to gender-affirming procedures performed on children.
 - Develop best practices (physical and mental) for medical detransition.
 - **HIV**
 - Continue to improve medical treatment and target long-term issues such as neurocognitive impairment over time.
 - Fund more research in **androgen insensitivity** and other **disorders of sexual development**.

Next Steps

The NIH appreciates all who participated in person and via audio and email. The information gathered from the listening session has informed the development of the draft goals for the fiscal years 2021- 2025 NIH SGM health research strategic plan, which will establish future agency-wide priorities in SGM health research. The SGMRO is seeking comments from the public on the draft scientific and operational goals. The [Federal Register Notice Request for Information](#) was published on December 13, 2019. Please share your comments with the SGMRO at SGMRO@nih.gov.

Appendix 1

SGM Health Research and Health Advocacy Participants

Advocates for Youth	Khadija Khan
Center for American Progress	Laura Durso, Ph.D.
Fenway Health	Sean Cahill, Ph.D.
GLSEN	Nhan Truong, Ph.D.
Human Rights Campaign	Tari Hanneman, M.P.A.
InterACT	Arlene Baratz, M.D.
National Center for Lesbian Rights	Julianna S. Gonen, Ph.D., J.D.
SAGE	Porsha Hall
Southern AIDS Coalition	Marissa Miller
Trevor Project	Sam Brinton, M.S.
UCSF Center for Transgender Excellence	Maddie Deutsch, M.D.
Whitman-Walker Health	Sandy James, J.D., Ph.D.

